

Wake Up Narcolepsy
INC.

The Monthly Wake Up

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Message from WUN Executive Director

Greetings,

While I am sad to see summer slipping away, I am excited with what lies ahead this fall for Wake Up Narcolepsy and our community. Last weekend, WUN raised almost \$10,000 during our successful cornhole fundraiser to support our camp for kids with Narcolepsy!

WUN's Conference & Patient Summit will take place in Rochester, MN, on September 9th, 2023. These in-person meetings are critical for PWNs.

We have over 100 people registered for in-person and almost 300 for remote. There is still time to register! We are fortunate to have such generous sponsors to bring this conference to the community at no-cost. We will also be celebrating World Narcolepsy Day on September 22nd. Please stay tuned for some exciting happenings to increase awareness on this day! The WUN and CCK camp will also take place on World Narcolepsy Day and there is still time to register!

Finally, as you may have seen, our volunteer program is up and running! We are so excited to see the enthusiasm and passion of our volunteers. We have 81 volunteers to date representing over 18 states and Canada. These committees are planning the following: local meet & greets, local educational programs, fundraisers and connecting patient families. Our dedicated volunteers are ready to get to know you and share what is happening in your area.

Please be on the lookout for an email from one of them. If you are interested in getting involved or wish to speak to another person with Narcolepsy or a family member living with Narcolepsy, please let us know and we will be happy to share information with you. Wake Up Narcolepsy is dedicated to funding research, creating great programming, supporting all those affected by Narcolepsy and their families, and providing resources and education to everyone.

Your ideas matter and we hope you'll join the WUN family. If you do not wish to be contacted, please let us know.

- Monica Gow



Monica Gow
WUN Co-Founder &
Executive Director

COMING UP - WUN Conference & Patient Summit

Wake Up Narcolepsy will be in Rochester, Minnesota, on September 9th, 2023, for our Conference & Patient Summit and we'd love to see you there!

It's not too late to register! Can't make it to Minnesota? Join us virtually! This is a no-cost event to ensure that our resources, connections and education are available to the community as a whole!

There will be a separate "teen track" available for younger attendees as well! More information can be found at

tinyurl.com/WUNConference2023



WAKE UP NARCOLEPSY
2023 CONFERENCE & PATIENT SUMMIT
September 9th - The Kahler Grand Hotel, Rochester, MN

<p>KEYNOTE SPEAKER 9:05 - 9:50 AM Medications for Narcolepsy: Present & Future MICHAEL H. SILBER, M.B., CH.B</p>	<p>BREAKOUT SESSION 2 1:40 - 2:40 PM Mental Health & Narcolepsy BHAKUPRAKASH KOLLA, MBBS, MD Medical Comorbidities & Narcolepsy DIEGO Z. CARVALHO, MD, MS Comorbid Sleep Disorders & Narcolepsy ERIK ST. LOUIS, MD</p>
<p>SPEAKER 1 9:50 - 10:35 AM Narcolepsy Symptoms & Diagnosis MITHRI JUNNA, MD</p>	<p>INDUSTRY SPEAKERS 2:50 - 3:20 PM</p>
<p>SPEAKER 2 10:45 - 11:30 AM Person with Narcolepsy Panel NICOLE JERAY, OLIVIA SIRPILLA THOMAS HECKMASTER, ANN KLAAS</p>	<p>WUN BREAKOUT SESSION 3:25 - 4:30 PM Youth Breakout HERO ANDERSON, TARA O'CONNOR Person w/ Narcolepsy Breakout NICOLE JERAY Parents Loved Ones Breakout ANNE SAMARAWICKRAMA</p>
<p>BREAKOUT SESSION 1 12:30 - 1:30 PM Transition of Care from Pediatrics to Adult JULIE BAUGHN, MD Pregnancy, Parenting with Narcolepsy MELISSA LIPFORD, MD Patient Perspective EMILY ROBINSON</p>	<p>FREE HYBRID EVENT - JOIN US: IN PERSON OR VIRTUAL. BREAKFAST, LUNCH & PARKING INCLUDED</p> <div><p>THANK YOU TO OUR SPONSORS</p></div> 

LAST CHANCE TO REGISTER - CCK & WUN Camp



Wake Up Narcolepsy
CCK CENTER FOR COURAGEOUS KIDS

FREE CAMP
FOR KIDS WITH NARCOLEPSY
& THEIR FAMILIES

SEPTEMBER 22ND-24TH, 2023

FEATURED SPEAKERS

Dr. Luis Ortiz
Liz Guckian

SUPPORT
NAPS
ARCHERY
FISHING
HORSEBACK RIDING
CONNECTIONS
UNDERSTANDING
SWIMMING
ARTS & CRAFTS

REGISTER NOW!
VOLUNTEER OPPORTUNITIES AVAILABLE



Our annual camp is just about one month away and we want to make sure that anyone who is interested gets their registration filled out! There is no longer a requirement for a physician statement when registering!

This is a FREE event! Join us to celebrate World Narcolepsy Day and make meaningful connections!

Visit wakeupnarcolepsy.org/camp for more details on registering!



BREAKING NEWS

There is no longer a requirement for a physician statement when registering for camp! Complete your registration today!

Cornhole Tournament

On August 19th, 2023, WUN hosted our 2nd annual Wicked Cornhole Tournament! Around 80 people attended and we raised just under \$10,000 for kids with Narcolepsy!

Thank you to everyone who attended and thank you again to our sponsors for making the event possible.

Read about it at
wakeupnarcolepsy.org/news/wun-cornhole-2023/



September Brown Bag Webinar

Join us for our September 2023 Brown Bag Webinar where Dr. Suzanne Stephens will be discussing:

**An Overview of
Narcolepsy Medications
in the US**

*Pre-registration is required.
Visit our website to reserve your
spot today!*



**Brown Bag
NARCOLEPSY
WEBINAR SERIES**

AN OVERVIEW OF NARCOLEPSY
MEDICATIONS IN THE US

SEPTEMBER
14TH 2PM
ET

Dr. Suzanne
Stephens



Thank you to our sponsors:



Upcoming Events

September 9th

*Wake Up Narcolepsy 2023
National Conference &
Patient Summit*

September 14th

*Brown Bag Webinar: An
Overview of Narcolepsy
Medications in the US*

September 22nd

World Narcolepsy Day

**September 22nd
- 24th**

WUN & CCK Camp

October 12th

*Brown Bag Webinar: Why Do
We Need to Sleep? The
Mystery Behind Sleep*

ONGOING

*Weekly support groups for
people with Narcolepsy and
Idiopathic Hypersomnia*

Clinical Trials

**Ontario Health:
At-Home Portable
Sleep Study Devices**

*We want to hear from you! Participate
in an interview on sleep disorders.
Please let us know if you are interested
by August 31st, 2023.*

Contact

samrawit.lemma@ontariohealth.ca

EXPLAIN Study

*The Behavioral Sleep Medicine Lab at
Northwestern University is researching
how family members are affected by
idiopathic hypersomnia and narcolepsy.*

Visit <https://redcap.link/explain>

**Boston Children's
Hospital Narcolepsy
Research Study for
Kids Ages 9 to 17**

*Our goal is to develop a clinical survey
that can improve the care of pediatric
narcolepsy.*

Contact

[NeuroSleepResearch-dl@
childrens.harvard.edu](mailto:NeuroSleepResearch-dl@childrens.harvard.edu)